The Twenty Eighth Report

Australia and New Zealand Dialysis and Transplant Registry

2005

The Twenty Eighth Report

Australia and New Zealand Dialysis and Transplant Registry

2005

Edited by

Stephen McDonald
and
Leonie Excell

Funded by

Commonwealth Department of Health and Ageing
Kidney Health Australia
New Zealand Ministry of Health

Supported by

AMGEN Australia Pty Ltd
Novartis Pharmaceuticals Australia Pty Ltd
Janssen-Cilag Pty Ltd
Fresenius Medical Care Australia
Roche Products Pty Ltd
Wyeth Australia Pty Ltd

Funding

ANZDATA Registry is funded by
Commonwealth Department of Health and Ageing
Kidney Health Australia
New Zealand Ministry of Health

Supported by unrestricted research Grants from
AMGEN Australia Pty Ltd
Novartis Pharmaceuticals Australia Pty Ltd
Janssen-Cilag Pty Ltd
Fresenius Medical Care Australia
Roche Products Pty Ltd
Wyeth Australia Pty Ltd

Coordinating Centre

ANZDATA Registry, C/- The Queen Elizabeth Hospital
28 Woodville Road, Woodville South,
Adelaide, South Australia, 5011

Phone (61-8) 8222.6704
Fax (61-8) 8222.6402 / 8222.6795
Email anzdata@anzdata.org.au
Web http://www.anzdata.org.au

Prof G Russ Chair of ANZDATA Executive
Dr S McDonald Executive Officer ANZDATA / Editor
Mrs L Excell Registry Manager / Editor
Mr B Livingston Computer Programmer
Ms V Shtangey Biostatistician
Mrs E Steinmetz Administration
Ms C Young Administrative Assistant

Printed in Adelaide, South Australia, 2005

AKF ACN 008 464 426

ISSN 1329-2870

Acknowledgments

ANZDATA Registry offers its most grateful appreciation to everyone who helped make this 28th Annual Report possible, especially the professionals and the staff of all the Renal Units and Tissue Typing Laboratories, upon whose reporting of data this enterprise ultimately depends.

Suggested Citation

An example of suggested citation for this report is as follows:

.. [Author's name] ..
Peritoneal Dialysis .. [page numbers] ..
ANZDATA Registry Report 2005
Australia and New Zealand Dialysis and Transplant Registry
Adelaide, South Australia.

Editors: Stephen McDonald and Leonie Excell

Publications based upon ANZDATA Registry information reported here or supplied upon request, must include the citation as noted above and the following notice:

The data reported here have been supplied by the Australia and New Zealand Dialysis and Transplant Registry. The interpreta tion and reporting of these data are the responsibility of the Editors and in no way should be seen as an official policy or interpretation of the Australia and New Zealand Dialysis and Transplant Registry.

APPENDIX I

APPENDIX II - AUSTRALIA (Available from website www.anzdata.org.au)

CONTENTS

APPENDIX III - NEW ZEALAND (Available from website www.anzdata.org.au)

CONTENTS

The ANZDATA Registry is pleased to present its 28th Annual Report which covers the calendar year 2004. Once again we are confident that there is 100% reporting of patients who have received dialysis and transplantation services in Australia and New Zealand. This confidence is because of the ongoing commitment to the Registry of renal units in those countries and the hard work that the staff of those units put into the timely and accurate provision of data.

The staff of the Registry have also continued to provide dedicated and excellent service. Lee Excell continues in her role as Manager of the Registry, Brian Livingston provides Information Technology expertise and data analysis and Lis Steinmetz provided administrative support.

There have been some changes to the staffing structure of the Registry in 2004. Bianca Byrne resigned her position as Biostatistician. Victoria Shtangey has been appointed in that role since November 2004. The role of the biostatistician is to provide statistical and database analysis and to allow the Registry to respond rapidly to requests for data from Contributors and others.

In addition Dr Stephen McDonald has been appointed as the Executive Officer of the Registry. As such he will have oversight of all the Registry activities as well as continuing to provide scientific and epidemiological input at all levels. The Registry is indeed fortunate to have Dr McDonald appointed in this role as his input in his previous appointment as Fellow in Epidemiology has been highly valued.

2004 saw the introduction of several innovations in the Registry. We now have a full year of collection for the Peritonitis Registry and a short report on this is contained in this volume. In addition there is now a full year collection of the Living Kidney Donor Registry and these data will be analysed at a later date. The Internet based data exchange scheme became operational in January 2005. This has enabled data entry from contributing units including the real time data entry of key events.

A change to the data collection timing for the Registry also has taken place in 2005. There is now only one annual data collection rather than the two as previously. The collection of key events such as new patient entry, transplantation, graft failure and death is another innovation which hopefully will allow up to date real time reporting of activity.

The major funding for the Registry continues to come from the Australian Commonwealth Department of Health and Ageing. Funds also are provided from Kidney Health Australia and the New Zealand Ministry of Health.

Non-tied Grants have also been received from AMGEN Australia Pty Ltd, Novartis Pharmaceuticals Australia Pty Ltd, Janssen-Cilag Pty Ltd, Fresenius Medical Care Australia, Roche Products, Pty Ltd, and Wyeth Australia Pty Ltd.

The production of this Report and the on going data collection, analysis and reporting activities of the Registry rely on the hard work of a number of individuals and Committees. The ANZDATA Registry Executive and the ANZDATA Registry Steering Committee membership are listed on page 7. In addition there are a number of smaller Working Groups which work in each of the specialty areas. These Groups have responsibility for defining the type of data to be collected from the contributing units as well as providing guidance for the analysis of that data.

Graeme Russ
Chair ANZDATA Executive

ANZDATA Registry Executive Committee

Professor Graeme Russ—Chair
Dr Stephen McDonald—Executive Officer
Mrs Leonie Excell—Manager
Mr Brian Livingston—Information Technologist
Ms Victoria Shtangey—Biostatistician
Mrs Lis Steinmetz—Administration

ANZDATA Registry Steering Committee

A/Professor Rowan Walker—Chair
Professor Graeme Russ
Dr Stephen McDonald
Mrs Leonie Excell
Dr Timothy Mathew (Kidney Health Australia Representative)
Dr Ian Dittmer (New Zealand Representative)
A/Professor Steven Chadban (Project Manager—Transplantation)
Professor Jeremy Chapman (Project Manager—Cancer)
Dr Angela Webster (Fellow in Cancer Epidemiology)
Professor David Johnson (Project Manager—Peritoneal Dialysis)
A/Professor Jonathan Craig (Project Manager—Paediatrics)
Dr Mark Marshall (Project Manager—Haemodialysis)
Dr Jeffrey Barbara
A/Professor Frank Ierino
Dr Grant Luxton
Dr Maureen Lonergan
Ms Denise Tomlinson (Nursing Representative)
To be advised (Client/Patient Representative)

ANZDATA Registry Working Groups

Transplant Working Group
A/Professor Steven Chadban (Project Manager)
Dr Stephen McDonald (Convenor)
Professor Graeme Russ
Dr Scott Campbell

Cancer Working Group
Professor Jeremy Chapman (Project Manager)
Dr Angela Webster (Fellow in Cancer Epidemiololgy)
Dr Stephen McDonald (Convenor)
Dr Jonathan Craig
Dr John Stewart

Peritoneal Dialysis Working Work
Professor David Johnson (Project Manager)
Dr Stephen McDonald (Convenor)
Dr Kate Wiggins
A/Professor Johan Rosman
Dr Fiona Brown

Paediatric Working Group
Dr Jonathan Craig (Project Manager)
Dr Stephen McDonald (Convenor)
Dr Paul Henning
Dr Stephen McTaggart

Haemodialysis Working Group
Dr Mark Marshall (Project Manager)
Dr Stephen McDonald (Convenor)
Dr John Agar
Dr Kevan Polkinghorne

PRIVACY

In December 2001 changes to the Commonwealth Privacy Act were introduced which have led to changes to the collection of personal information. Essentially these extend to the private sector a number of changes based around 10 "National Privacy Principles" (NPP's). A detailed exposition of these can be found at the Privacy Commissioner's website (www.privacy.gov.au). Briefly, however, health information is treated as "sensitive" information, which must usually be collected and handled with consent of the person, unless certain conditions are met. Patients are entitled to view the information the Registry holds about them, and request alterations if the data is thought to be inaccurate.

Each Australian State has also enacted similar provisions which cover practice and patients in public hospitals.

ANZDATA does not release data identifiable by patient name. Results are published/ released in tabular or graphic format. On occasion, when data identifying particular hospitals is involved, consent from the Director of the relevent renal unit is sought prior to the release of information.

COLLECTION OF DATA

ANZDATA spent some time during 2002 formulating an appropriate response to these issues including seeking advice from a variety of sources. The approach taken has been that of a "opt-out" consent, whereby patients are distributed information outlining the nature and purpose of the information collected, offered an opportunity to view that data and ask questions, and the opportunity to request withdrawal of part or all of their data. This approach is explicitly suggested for Registries by the Privacy Commissioner in his "Guidelines for the Health Sector". To this end ANZDATA has circulated to all participating hospitals a patient information sheet (see opposite), for each hospital to use (or a locally modified version if appropriate) to inform patients.

At the time of data collection each unit is asked to certify that they have complied with measures under the relevant privacy measures.

ANZDATA REGISTRY
AUSTRALIA AND NEW ZEALAND DIALYSIS AND TRANSPLANT REGISTRY

C/- The Queen Elizabeth Hospital
28 Woodville Road
Woodville South, 5011
South Australia

Phone: (08) 8222.6704
Fax: (08) 8222.6402
Email: anzdata@anzdata.org.au
Web: http://www.anzdata.org.au

Important Privacy Information

As part of routine medical care of people receiving treatment with dialysis or kidney transplantation, your kidney specialist collects certain information about the patients they treat. All kidney specialists throughout Australia and New Zealand report this information every twelve months to the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). ANZDATA collects the information for the purpose of monitoring treatments and performing analyses to improve quality of care for people with kidney failure.

1. What is ANZDATA ?

ANZDATA is an organization set up by Kidney Health Australia and the Australia and New Zealand Society of Nephrology to monitor dialysis and transplant treatments. ANZDATA is funded by the Australian and New Zealand Governments and Kidney Health Australia.

2. What information is collected about you ?

This information includes your name, age, gender, racial origin, hospital of treatment, some aspects of your medical condition (such as whether you have diabetes) and details about the type of kidney treatment you are receiving (dialysis or transplant).

We **DO NOT** collect details about your address, telephone number, medical insurance, or non-medical matters such as occupation, income, etc.

3. Is personal data ever released ?

The identity of people in the database **IS NOT released publicly nor in any reports**. Measures have been put into place to ensure the security of all collected information.

4. What is this information used for ?

The information is used primarily for quality assurance, investigating patterns of kidney disease, and planning appropriate health services. We release reports on a variety of topics, including an Annual Report examining the rates and treatment of kidney failure in Australia and New Zealand. We also have a major role in ensuring the quality of patient care by sending to each kidney unit each year a report outlining their activity. These reports also compare the outcome of the treatment they provide with that of other units throughout the two countries. Reports are also produced at a state and national level, and from time to time analyses are also produced for renal units, government health departments and industry concentrating on particular aspects of renal failure management e.g. peritoneal dialysis, transplantation, haemodialysis.

5. Can you see what personal information ANZDATA collects and the reports that it produces ?

Individuals are able to view their own information on request. You can request alterations if you believe it is inaccurate. You may also opt not to have your treatment included in this database, and you should let your kidney specialist know if this is the case. You can also choose not to have some information (e.g. racial origin) recorded. However, if your information is not included in the Registry, the ability to compare results in Australia and New Zealand or to analyse the results of different treatment methods and for different patient types (e.g. diabetics) will be compromised.

The national reports and much other material produced by ANZDATA are available free on the Internet at www.anzdata.org.au, or they can be sent to you on request to the address above. Your kidney specialist will also have copies of many of the reports.

If you wish to discuss any of the issues raised here, please let your doctor know or telephone the ANZDATA Registry direct on [08] 8222 6704. You may also write to us (ANZDATA Registry, C/- The Queen Elizabeth Hospital, 28 Woodville Road SA 5011) or send us an e-mail (anzdata@anzdata.org.au).

GUIDELINES FOR DATA RELEASE

The policy for release of data to investigators, renal units and others was revised during 2002 and is summarised on the Website. ANZDATA encourages the analysis, use and citation of its data, and receives many data requests annually which vary in size and complexity. At times these overwhelm the limited resources within the Registry, and must be prioritised. Generally, formal requests for data are preceded by a period of consultation with a member of the Registry staff. Requests are welcome from Renal Physicians, other staff members of Renal Units, Charitable Bodies, Academic Institutions, Government Departments and Industry. Requests dealing with identifiable Hospital data will only be fulfilled with the explicit consent of the Heads of the relevant Hospital Units.

ATTRIBUTION OF PUBLICATIONS

The policy on attribution of publications which incorporate ANZDATA sourced data was revised during 2002, following a period of consultation with participating physicians.

Where a member of a participating unit has analysed data provided by ANZDATA and subsequently prepared a manuscript, then "ANZDATA Registry" should be acknowledged as a secondary institution in addition to the author's Hospital or University. This applies whether the primary data analysis is performed by the author or by ANZDATA staff. Where the author is an ANZDATA office holder or staff member then the primary attribution should be "ANZDATA Registry".

Where ANZDATA data is only a minor portion of the work, then it may be more appropriate to acknowledge the source explicitly in the "Acknowledgements" section.

In both cases the disclaimer on page ii of this report should be included.

In all cases the source and treatment of the data should be made clear in the "Methods" section. Preferably the abstract (and keywords if applicable) should also include "ANZDATA" which would allow for searching Registry publications.

Associate Professor Kym Bannister
Director Renal Unit
Royal Adelaide Hospital, Adelaide, South Australia 5000

Associate Professor Steven Chadban
Nephrologist and Transplant Physician
Department of Renal Medicine, Royal Prince Alfred Hospital,
Missenden Road, Camperdown, New South Wales, 2050

Professor Jeremy Chapman
Director Renal Unit
Westmead Hospital, Cnr Hawkesbury & Darcy Road, Westmead, New South Wales, 2145

Associate Professor Jonathan Craig
Paediatric Nephrologist
The Children's Hospital at Westmead, New South Wales, 2006

Mrs Leonie Excell
ANZDATA Registry Manager
The Queen Elizabeth Hospital,Woodville, South Australia, 5011

Dr Paul Henning
Director Renal Unit
Women's and Children's Hospital, North Adelaide, South Australia, 5006

Professor David Johnson
Director Renal Unit
Princess Alexandra Hospital, Ipswich Road, Woolloongabba, Queensland, 4102

Mr Brian Livingston
ANZDATA Registry Information Technologist
The Queen Elizabeth Hospital, Woodville, South Australia, 5011

Dr Mark Marshall
Nephrologist, Renal Unit
Middlemore Hospital, Otahuhu, Auckland, New Zealand

Dr Stephen McDonald
Executive Officer, ANZDATA
The Queen Elizabeth Hospital,Woodville, South Australia, 5011

Dr Stephen McTaggart
Paediatric Nephrologist, Renal Unit
Princess Alexandra Hospital, Ipswich Road, Woolloongabba, Queensland, 4102

Professor Graeme Russ
Chair ANZDATA Executive, Director Renal Unit
The Queen Elizabeth Hospital,Woodville, South Australia, 5011

Ms Victoria Shtangey
ANZDATA Registry Biostatistician
The Queen Elizabeth Hospital,Woodville, South Australia, 5011

Dr Angela Webster
Research Fellow, Centre for Kidney Research, The Children's Hospital at Westmead,
Room 13, Clinical Sciences Level 2, Locked Bag 4001, Westmead, New South Wales, 2145

These definitions apply throughout this report unless otherwise stated.

1. Wording

Throughout this report 'treatment' refers to renal replacement therapy, including haemodialysis, peritoneal dialysis and transplantation

HD = haemodialysis
APD = automated peritoneal dialysis
CAPD = continuous ambulatory peritoneal dialysis
ESKD = end stage kidney disease

2. Data collection

ANZDATA collects information from all renal units in Australia and New Zealand every 12 months. Currently this is by a paper-based system, with manual completion of the form and manual data entry. No formal audit mechanism is in place at this stage.

For transplants, HLA matching and panel reactive antibodies are obtained direct from the Tissue Typing laboratories in each State.

3. Inclusion criteria

Included in the Registry are all patients receiving renal replacement therapy where the intention to treat is long-term, i.e. medical opinion is that renal function will not recover. Cases of acute renal failure are excluded. People who move overseas permanently are censored at date of last treatment (or departure in the case of transplant recipients).

4. Modality attribution

The initial mode of dialysis is determined at 90 days after first treatment, to allow for early changes and maturation of access. Other transfers (between modalities, or from satellite to hospital haemodialysis etc.) are not analysed if less than 30 days, except for transfers between dialysis centres to which a 60 day rule is applied to allow for holiday movements.

5. Underlying renal disease

This is recorded by the treating hospital according to a modified EDTA coding system (details on back of survey form).

6. Deaths

Death rate is predominantly reported as number of patients died/total number of years of treatment of all patients treated at any time during the year. It is expressed as deaths per 100 patient years (pt yrs) at risk.

7. Comorbid conditions

These are recorded by the treating hospital. No definitions are supplied; the treating clinician is asked to record whether the patient has coronary artery disease, chronic lung disease, cerebrovascular disease, peripheral vascular disease or diabetes according to their clinical opinion on a yes / suspected / no basis.

8. Transplant Waiting List

The active transplant waiting list includes listing at any stage during the survey period.

9. Derived measures

9.1 Haemoglobin

Haemoglobin is recorded as the last available measurement before the end of the survey period.

9.2 Erythropoietic agents

Erythropoietin agent use is recorded as "yes" if these agents were used at any time during the survey period.

9.3 Iron Studies

Iron studies are requested within the last three months of the survey period.

9.4 Estimated creatinine clearance

Where creatinine clearance is estimated from serum creatinine at entry or post transplantation, the Cockroft-Gault equation is used [1].

$$Cl_{Cr}=(140-age)*weight / (814*Cr_{serum})[*0.85 \text{ if female}]$$

The weight term used for this is lean body mass, calculated using the equation LBW=(0.9*[height-152])+(50 if male, 45.5 if female) [2].

9.5 Urea reduction ratio / Kt/V

Results are requested in one of these formats, using the stop flow method on a mid-week dialysis. Single pool Kt/V is collected, along with the method used.

For conversion of URR to Kt/V urea the formula used [3] is

Kt/V = 0.023*PRU - 0.284 (note that PRU = percent reduction in urea and not URR).

9.6 Body Mass Index

Body mass index (BMI) is calculated as $\frac{\text{weight (kg)}}{(\text{height (m)})^2}$

The standard NH&MRC categories are used: underweight <20 kg/m^2 normal 20-24.9 kg/m^2 overweight 25-29.9 kg/m^2 obese >=30 kg/m^2

9.7 Peritoneal Dialysis measures

These are the standard measures, often calculated by computerised patient management programs.

9.7.1 Residual renal function

The measure used is the arithmetic mean of urea and creatinine clearance from a 24-hour urine collection and serum creatinine and urea.

9.7.2 Peritoneal equilibration test

The ratio of dialysate to plasma glucose is used, following a 4 hour dwell of a 2 litre 2.5% bag of dialysate, performed within 6 months after initiation of peritoneal dialysis.

10. Rates & Measures

10.1 Incidence rates

Except where otherwise stated, quoted incidence rates are per calendar year, and are expressed per million population.

10.2 Prevalence rates

Except where otherwise specified, prevalence rates are point prevalence rates at 31st December 2004.

10.3 Population denominator

The population estimates used are the estimated resident populations (ERP) for the year 2004, released by the Australian Bureau of Statistics and Statistics New Zealand. Figures used are those for the June quarter.

For both countries, the statistics bureaux record indigenous status on a self-identification basis. For Australia, there has been considerable change in the propensity to self-identify as indigenous, such that a number of estimates are released by the ABS [4]. For this report, the low range projections have been used.

10.4 Survival rates

For transplant recipients, survival rates exclude those who were transplanted overseas or were recipients of multiple organ grafts.

Graft survival (unless otherwise qualified) includes both cessation of graft function (i.e. return to dialysis) and patient death.

Patient survival for transplant recipients - rates for fixed periods are calculated according to the life-table method and include an adjustment to the risk-set of ½ of those censored without failure over the interval to create an “average” risk set.

10.5 Graft Survival

For outcomes of kidney transplants, graft failure includes both loss of graft function (i.e. return to dialysis) and death of patients (with graft function). Calculations of patient survival for transplant recipients includes all subsequent modalities (i.e. deaths after graft failure are included). Patients transplanted overseas are excluded from calculations.

10.6 Dialysis Survival

Patient and technique survivals for haemodialysis and peritoneal dialysis are based on the dialysis modality at 90 days after first treatment for patients not grafted during that period. Patients are followed up until they are either grafted (at which point they are censored) or until they have a 'permanent' change of dialysis modality or until death or most recent follow up date. A 'permanent' change of dialysis is defined as any change in excess of 30 days.

Peritonitis survivals are calculated from first peritoneal dialysis (ignoring all earlier treatments) to date of first peritonitis episode. If there were no episodes of peritonitis then calculation is censored at change of treatment from peritoneal dialysis to haemodialysis or transplantation. Peritoneal dialysis includes automated peritoneal and continous ambulatory peritoneal dialysis. Excluded are patients who had peritonitis before commencing peritoneal dialysis.

10.7 Death and other event rates

Rates are expressed per 100 person years at risk (unless otherwise stated).
Some analyses include survival of all patients, others exclude the first 90 days of followup. This is stated in the individual analyses.

10.8 Age standardisation

All rates are crude, not age-standardised. The age distribution of the populations for Australia and New Zealand are given in Appendix I.

11. Database

Data is stored on a relational database using ORACLE version 8I.

12. Statistics

Statistical analyses were performed using SPSS release version 10.0.7 and Stata version 9.

13. References

1. Cockcroft DW, Gault MH: Prediction of creatinine clearance from serum creatinine. Nephron 1976: 16;31-41.
2. Zasadny KR, Wahl RL: Standardized uptake values of normal tissues at PET with 2-[fluorine-18]-fluoro-2-deoxy-D-glucose: variation with body weight and method for correction. Radiology 1993: 189;847-850.
3. Basile C, Casino F, Lopez T: Percent reduction in blood urea concentration during dialysis estimates Kt/V in a simple and accurate way. Am J Kidney Dis 1990: 15;40-45.
4. Australian Bureau of Statistics: Experimental Projections of the Aboriginal and Torres Strait Islander Population. Canberra, ABS Cat. No. 3101.0, 2002.

QUEENSLAND
Allamanda Private Hospital (Nephrocare)
Bundaberg Base Hospital
Cairns Base Hospital
Caloundra Private Hospital
Goldcoast Hospital
Henry Dalzieal Dialysis Centre (Greenslopes) (Baxter)
Hervey Bay Hospital
John Flynn Hospital
Mackay Base Hospital
Nambour Hospital
Nambour Private Hospital
Pine Rivers Private Hospital
Princess Alexandra Hospital
Rockhampton Base Hospital
Royal Brisbane Hospital
The Townsville Hospital
Toowoomba Hospital
Wesley Private Hospital

NEW SOUTH WALES
Dubbo Base Hospital
East Coast Renal Service
Prince of Wales Hospital
St. George Hospital
St. Vincent's Hospital
Sydney Children's Hospital
Wollongong Hospital
Gosford Hospital
Hunter New England Health
Lismore Hospital
Mater Misericordiae Hospital
Royal North Shore Hospital
South West Sydney Renal Services
Liverpool Hospital
Statewide Renal Services
Concord Hospital
Royal Prince Alfred Hospital
Sydney Adventist Hospital
Tamworth Hospital
The Children's Hospital at Westmead
The Tweed Hospital
Western Renal Network
Westmead Hospital
Orange Base Hospital

AUSTRALIAN CAPITAL TERRITORY (ACT)
The Canberra Hospital

VICTORIA
Alfred Hospital
Austin Health
Epworth Hospital
Geelong Hospital
Monash Medical Centre – Adult
Monash Medical Centre – Paediatric
North West Dialysis Service
Royal Melbourne Hospital
Royal Children's Hospital
St. Vincent's Hospital

TASMANIA
Launceston General Hospital
Royal Hobart Hospital

SOUTH AUSTRALIA
Flinders Medical Centre
The Queen Elizabeth Hospital
Royal Adelaide Hospital
Women's and Children's Hospital

NORTHERN TERRITORY
Royal Darwin Hospital
Alice Springs Hospital

WESTERN AUSTRALIA
Fremantle Hospital
Hollywood Private Hospital
Princess Margaret Hospital for Children
Royal Perth Hospital
Sir Charles Gairdner Hospital
St. John of God Private Hospital

NEW ZEALAND
Auckland City Hospital
Starship Children's Hospital
Christchurch Hospital
Dunedin Hospital
Middlemore Hospital
Palmerston North Hospital
Taranaki Base Hospital
Waikato Hospital
Wellington Hospital
Whangarei Area Hospital

QUEENSLAND

Princess Alexandra Hospital (Adult & Paediatric)
Director of Transplantation - Dr David Nicol
Ipswich Road
Woolloongabba 4102

NEW SOUTH WALES

Hunter New England Health
Director of Transplantation - Professor Adrian Hibberd
Lookout Road
New Lambton Heights
Newcastle 2304

Prince of Wales Hospital
Director - Professor John Charlesworth
Barker Street
Randwick 2031

Royal North Shore Hospital
Director - Dr David Waugh
Pacific Highway
St Leonards 2065

Royal Prince Alfred Hospital
Director of Transplantation - A/ Professor Steven Chadban
Missenden Road
Camperdown 2050

St. George Hospital
Director of Transplantation - Professor John Kelly
Montgomery Street
Kogarah 2217

St. Vincent's Hospital
Director - Dr Tim Furlong
Victoria Street
Darlinghurst 2010

Sydney Children's Hospital
Director - Dr Andrew Rosenberg
C/- Department of Nephrology
Prince of Wales Hospital
Barker Street
Randwick 2031

The Children's Hospital at Westmead
Director - Dr Elisabeth Hodson
Cnr Hawkesbury and Hainsworth Street
Westmead 2145

Westmead Hospital
Director - Professor Jeremy Chapman
Cnr Hawkesbury and Darcy Road
Westmead 2145

VICTORIA

Alfred Hospital
Director - Professor Napier Thomson
Commercial Road
Prahran 3181

Austin Health
Director - Dr David Power
Burgundy Road
Heidelberg 3084

Monash Medical Centre (Paediatric)
Director - Dr Amanda Walker
246 Clayton Road
Clayton 3165

VICTORIA cont

Monash Medical Centre (Adult)
Director - Professor Robert Atkins
246 Clayton Road
Clayton 3165

Royal Children's Hospital
Director - Dr Colin Jones
Flemington Road
Parkville 3052

Royal Melbourne Hospital
Director - Professor Gavin Becker
Parkville 3052

St. Vincent's Hospital
Director - Professor Robyn Langham
41 Victoria Parade
Fitzroy 3065

SOUTH AUSTRALIA

The Queen Elizabeth Hospital
Director - Professor Graeme Russ
28 Woodville Road
Woodville 5011

Women's and Children's Hospital
Director - Dr Paul Henning
72 King William Road
North Adelaide 5006

WESTERN AUSTRALIA

Princess Margaret Hospital for Children
Director - Dr Ian Hewitt
Roberts Road
Subiaco 6008

Royal Perth Hospital
Director - Dr Ashley Irish
Wellington Street
Perth 6001

Sir Charles Gairdner Hospital
Director - Dr Brian Hutchison
Verdun Street
Nedlands 6009

NEW ZEALAND

Auckland City Hospital
Director - Dr John Collins
Park Road
Grafton, Auckland

Christchurch Hospital
Director - Dr Richard Robson
Riccarton Avenue
Christchurch

Starship Children's Hospital
Director - Dr William Wong
Park Road
Grafton, Auckland

Wellington Hospital
Director - Dr Grant Pidgeon
Riddiford Street
Newtown, Wellington South

QUEENSLAND

Atherton Satellite - Cairns Base Hospital
Cairns Private Hospital Satellite - Cairns Base Hospital
Home Hill Satellite - Townsville Hospital
Innisfail Hospital - Cairns Base Hospital
Ipswich Satellite - Princess Alexandra Hospital
Logan Satellite - Princess Alexandra Hospital
Mt. Isa Satellite - Townsville Hospital
Noosa Satellite - Nambour Hospital
Palm Island Satellite - Townsville Hospital
Redcliffe Satellite - Royal Brisbane Hospital
Robina Satellite - Goldcoast Hospital
St Andrew's Private Hospital (Gambro) - Toowoomba Hospital
Vincent Satellite - Townsville Hospital

NEW SOUTH WALES

Ballina Satellite - Lismore Hospital
Bankstown Hospital - South West Sydney Renal Services
Bathurst Hospital - Orange Hospital
Blacktown Satellite - Westmead Hospital
Brewarrina Hospital
Campbelltown Satellite - South West Sydney Renal Services
Coffs Harbour Base Hospital
Coonamble Hospital
Dame Eadith Walker - Statewide Renal Services
Dubbo Base Hospital
Eora Satellite - Prince of Wales Hospital
Grafton Hospital - Lismore Hospital
Griffith Base Hospital - State Wide Renal Services
Invarell Satellite - Tamworth Hospital
Lakehaven Satellite - Gosford Hospital
Lanceley Cottage - Royal North Shore Hospital
Lindfield Dialysis Unit (Gambro)
Liverpool Community Centre - South West Sydney Renal Services
Macleay Dialysis Centre - Kempsey - Hunter New England Health
Maitland Hospital - Hunter New England Health
Moree Satellite - Tamworth Hospital
Muswellbrook - Hunter New England Health
Nita Reed Community Dialysis (Taree) - Hunter New England Health
Norfolk Island Hospital - Statewide Renal Services
Orange Base Hospital - Westmead Hospital
Port Macquarie Community Dialysis Centre
Port Macquarie Hospital
Shellharbour - Wollongong Hospital
Shoalhaven Satellite (Nowra) - Wollongong Hospital
Singleton Satellite - Hunter New England Health
Sydney Dialysis Centre
Wagga Wagga Base Hospital
Wansey Satellite - Hunter New England Health
Wentworth Dialysis Centre - Westmead Hospital

AUSTRALIAN CAPITAL TERRITORY (ACT)

Canberra Community Dialysis Centre

VICTORIA

Angliss Hospital
Ararat Hospital
Austin Training Satellite - Austin Health
Bacchus Marsh Hospital
Bairnsdale Hospital
Ballarat Health Services
Bendigo Hospital
Berwick Hospital
Broadmeadows Satellite
Brunswick Satellite
Casey Satellite
Casterton Hospital
Caulfield General Medical Centre
Coburg Satellite
Cohuna Hospital
Colac Hospital
Corryong Satellite
Cranbourne Satellite
Dandenong Satellite
Daylesford Hospital
Echuca Hospital
Epping Dialysis Unit
Epworth Hospital
Forest Hill Dialysis Centre (Nephrocare)
Frankston Satellite
Gambro - Diamond Valley Hospital
Goulburn Valley Hospital
Hamilton Hospital
Hastings Hospital
Heidelberg - Austin Health
Horsham Satellite
Kew Private Dialysis Centre (Baxter)
Kyneton Hospital
La Trobe Regional Satellite

VICTORIA CONT...

Lorne Hospital
Malvern Dialysis Centre (Nephrocare)
Maryborough District Health Service
Mildura Hospital
Moorabbin Satellite
Myrtleford Hospital
Nauru (overseas) - Alfred Hospital
Nauru (overseas) - Monash Medical Centre Adult
Newcomb Satellite
North East Kidney Service - Austin Health
Northern Hospital Satellite
Omeo District Hospital
Orbost Hospital
Peter James Centre
Portland Hospital
Rosebud Hospital
Sale Hospital
Sandringham Satellite
Seymour Hospital
South Geelong Renal Unit - Geelong Hospital
St. Arnaud Hospital
St. George's Hospital
Sunshine Satellite
Swan Hill Hospital
Terang Satellite
Wangaratta Hospital
Warnnambool Hospital
Werribee Mercy Hospital
Western Gippsland Hospital
Williamstown Satellite
Wodonga Regional Health Service
Wonthaggi Hospital
Yarawonga District Hospital
Yarram Hospital

TASMANIA

North West Renal Unit, Burnie - Launceston Hospital

SOUTH AUSTRALIA

Berri Hospital
Hampstead Rehabilitation Satellite
Hartley Private Hospital (Nephrocare)
Lyell McEwin Satellite
Modbury Private Dialysis Centre (Nephrocare)
Mount Gambier Satellite
Murray Bridge Hospital
Noarlunga Satellite
Payneham Private Dialysis Centre (Baxter)
Port Augusta Hospital
Port Lincoln Satellite Centre
Wayville Satellite Centre

NORTHERN TERRITORY

Bathurst Island Hospital - Royal Darwin Hospital
Community Health Centre - Alice Springs Hospital
Katherine Dialysis Unit - Royal Darwin Hospital
Nightcliff Community Centre - Royal Darwin Hospital
Palmerston Satellite - Royal Darwin Hospital
Tennant Creek Hospital - Alice Springs Hospital

WESTERN AUSTRALIA

Albany Satellite
Armadale Satellite
Bunbury Satellite
Geraldton Hospital
Joondalup Satellite Unit
Kalgoorlie Dialysis Unit
Kimberley Dialysis Centre - Royal Perth Hospital
Melville Satellite
Midland Private Dialysis Centre (Baxter)
Peel Health Campus - Mandurah
Pilbara Dialysis Unit [Port Hedland] - Royal Perth Hospital
Royal Perth Rehabilitation Hospital - Royal Perth Hospital

NEW ZEALAND

Bay of Islands Hospital - Whangarei Hospital
Carrington Satellite - Auckland City Hospital
Greenlane Hospital - Auckland City Hospital
Manukau Satellite - Middlemore Hospital
Middlemore Hospital
Porirui Satellite - Wellington Hospital
Tauranga Hospital - Waikato Hospital
Waitakere Satellite - Auckland City Hospital

During the calendar year 2004 (the period covered by this Report), the following manuscripts based on ANZDATA material appeared in peer-reviewed journals.

Lim WH.
Is there a role for peritoneal dialysis in remote aboriginal patients with end-stage renal disease in Australia?
Nephrology 2004; 9:S126-8.

McDonald S, Collins J, Rumpsfeld M, Johnson D.
Obesity is a risk factor for peritonitis in the Australian and New Zealand peritoneal dialysis patient populations.
Perit Dial Int 2004; 24:340-346.

McDonald S.
Indigenous transplant outcomes in Australia: What the ANZDATA Registry tells us.
Nephrology 2004; 9 Suppl 4:S138-43.

McDonald SP, Craig JC.
Long term survival of children with end-stage renal disease.
N Engl J Med 2004; 350:2654-2662.

McDonald SP, Marshall MR, Kerr PG, Russ GR.
Erythropoietic agents, iron and hemoglobin - What happens beyond the trial setting: Observational data from the ANZDATA Registry.
Hemodialysis Int 2004; 8:257-264.

Polkinghorne KR, McDonald SP, Atkins RC, Kerr PG.
Vascular access and all-cause mortality: a propensity score analysis.
J Am Soc Nephrol 2004; 15:477-86.

Rumpsfeld M, McDonald SP, Purdie DM, Collins J, Johnson DW.
Predictors of baseline peritoneal transport status in Australian and New Zealand peritoneal dialysis patients.
Am J Kidney Dis 2004; 43:492-501.

Stewart JH, McCredie MR, McDonald SP.
Incidence of end-stage renal disease in overseas-born, compared with Australian-born, non-indigenous Australians.
Nephrology 2004; 9:247-252.

Stewart JH, McCredie MR, Williams SM, McDonald SP.
Interpreting incidence trends for treated end-stage renal disease: Implications for evaluating disease control in Australia.
Nephrology 2004; 9:238-246.

Stewart JH, McCredie MRE, McDonald SP.
The incidence of treated end-stage renal disease in New Zealand Maori and Pacific Island people and in Indigenous Australians.
Nephrol Dial Transplant 2004; 19:678-85.

2005 AUST. & N.Z. DIALYSIS AND TRANSPLANT SURVEY

THIS SECTION FOR ALL PATIENTS

REGISTRY NUMBER | **1** INITIAL HOSPITAL: Hospital/State | Hosp. Unit No. | CURRENT PARENT HOSPITAL: Hospital/State | Hospital Unit No | Physician (Optional)

2 Surname | Given Names | **3** DATE OF BIRTH | **4** SEX

5 RACIAL ORIGIN (Record from list) | OTHER | **6** PRIMARY RENAL DISEASE (Record from list) | OTHER | **7** BIOPSY Y/N | **8** SE. CREATININE AT ENTRY

9 COUNTRY OF BIRTH (IF Australia or NZ - Tick box): Aust | NZ | OTHER COUNTRY (Please specify) | **10** POSTCODE AT ENTRY | POSTCODE AT END SURVEY

11 CO-MORBID CONDITIONS AT ENTRY

LATE REFERRAL <3 MTHS BEFORE FIRST TREATMENT (Y/N) | HEIGHT (cms) | WEIGHT (kg) | CIGARETTE SMOKING N=Never F=Former C=Current

KIDNEY HEALTH AUSTRALIA

DISEASE AT ENTRY AND DURING CURRENT SURVEY

Y=Yes N=No S=Suspected

	CHRONIC LUNG Y/S/N	CORONARY ARTERY Y/S/N	PERIPHERAL VASCULAR Y/S/N	CEREBRO VASCULAR Y/S/N	DIABETES N=No O=Type 1 Insulin dependent P=Type 2 Non Insulin requiring Q=Type 2 Insulin requiring
AT ENTRY					
LAST					
CURRENT					

OTHER CO-MORBID CONDITIONS (Write in)

AT ENTRY	
PREVIOUS ENTRIES	
CURRENT	

12 CENTRE OF TREATMENT Enter geographical location at Death or End of survey

	HOSPITAL / CENTRE NAME (Write in or Tick if same)	CENTRE CODE	DATE TRANSFER
CURRENT			
LAST			

13 HEPATITIS C ANTIBODY

1=Positive 2=Negative 3=Not done	CURRENT	LAST

14 COURSE OF TREATMENT - COMPLETE ACCORDING TO CODE

A Hospital/Outpatient APD / IPD
C Satellite APD / IPD
E Home APD / IPD
L Hospital/Outpatient CAPD
M Home CAPD
B Hospital HD
D Satellite HD
F Home HD
G Transplant in AUST/NZ
H Date of last post graft dialysis
X Transplant Overseas
I Graft function Temporary/Permanently ceased (Date return to dialysis)
J Own kidney function recovered. Dialysis ceased
K Date of last visit if lost to follow up
Z DATE OF DEATH

	CODE	DAY	MTH	YR		CODE	DAY	MTH	YR		CODE	DAY	MTH	YR
1st					16th					31st				
2nd					17th					32nd				
3rd					18th					33rd				
4th					19th					34th				
5th					20th					35th				
6th					21st					36th				
7th					22nd					37th				
8th					23rd					38th				
9th					24th									
10th					25th									
11th					26th									
12th					27th									
13th					28th									
14th					29th									
15th					30th									

15 CANCER EVER? Y/N If Yes, enter separate Cancer Form

16 CAUSE OF DEATH (Record from list) | OTHER

17 WAS GRAFT SUSTAINING LIFE? Without dialysis at time of death Y=Yes N=No

18 PARENTHOOD HAS THIS PATIENT BECOME PREGNANT OR FATHERED A CHILD DURING THIS SURVEY Y=Yes N=No If Yes, please complete the Pregnancy Outcome sheet | DATE OF LAST OUTCOME

THIS SECTION FOR ALL PATIENTS DIALYSED AT ANY TIME DURING THIS SURVEY PERIOD

19 TYPE OF DIALYSIS (See list) | **20** DRY WEIGHT AT LAST DIALYSIS kg (HD and PD Patients) | **21** UNCORRECTED CALCIUM mmol/l (See instructions on the back of the form) | **22** PHOSPHATE mmol/l | **23** HAEMOGLOBIN g/l Last Available | **24** EPO AGENT Y=Yes N=No | **25** FERRITIN ug/l Within last 3 mths of Survey or record not done | **26** % SATURATION IRON (Transferrin Saturation)

HAEMODIALYSIS

27 DIALYSER BRAND (Write in) CODE | BRAND NAME AND MODEL | **28** BLOOD FLOW RATE Pump Speed mls/min | **29** SESSIONS PER WEEK | **30** HOURS PER SESSION | **31** UREA REDUCTION or Kt/V Method (See List) | Value

32 ACCESS IN USE (Functioning only) Enter for **ALL PATIENTS ON HAEMODIALYSIS** AT ANY TIME DURING THIS SURVEY PERIOD

AT FIRST HD | AT LAST HD | DECLOTTED during Survey | REVISED during Survey

1=Native 2=Synthetic 3=Tunnel CV Catheter 4=Non Tunnel CV Catheter

Y=Yes N=No S=Surgical A=Angioplasty B=Both D=Declotted and revised

IN THE EVENT OF THE PATIENT HAVING BOTH HD AND PD, AND A TRANSPLANT DURING THE SURVEY COMPLETE SECTIONS 19-41 INCLUSIVE

ALL PERITONEAL DIALYSIS

33 PET TEST (Once only) Within first 6 mths (Dx/Plasma Creatinine at 4 hours) | **34** CONNECTION SYSTEM CODE | (Write In) | **35** PERITONITIS DATE OF FIRST EPISODE | **36** NUMBER OF EPISODES OF PERITONITIS During this Survey | **37** TOTAL VOLUME OF WEEKLY EXCHANGES (Litres/week)

38 DIALYSATE **ONLY** (Creatinine Clearance) Adjusted for Body Surface Area (Litres/week/1.73 m²) | Range 10-200 Litres/week | **39** DIALYSATE **ONLY** WEEKLY Kt/V (Range 0.1 - 5.0) | **40** RESIDUAL RENAL FUNCTION (Creatinine Clearance) Adjusted for Body Surface Area (Litres/week/1.73 m²) | **41** REASON FOR TRANSFER DURING SURVEY (Record from list) From CAPD to APD From APD to CAPD From any PD to HD | 1st | 2nd | 3rd | 4th

CURRENT GRAFT (IN THE EVENT OF BOTH GRAFT FAILURE AND RETRANSPLANT IN THIS SURVEY – USE A NEW FORM)

42 GRAFT NUMBER | **43** DATE OF THIS TRANSPLANT | **44** REFERRING HOSPITAL | **45** DONOR HOSPITAL | **46** TRANSPLANT HOSPITAL | **47** RECIPIENT ANTIBODY STATUS AT GRAFT CMV EBV 1=Positive 2=Negative 3=Not done | **48** NUMBER REJECTION EPISODES THIS SURVEY (Complete acute rejection form for each episode) (at any time)

49 DONOR DETAILS SOURCE (See list) | AGE | SEX | **50** TOTAL ISCHAEMIA (Hours) | **51** IMMEDIATE FUNCTION (See list) | **52** DISEASE IN GRAFT If Yes (See list) | **53** DATE FIRST PROVEN (eg. Graft biopsy) | **54** CAUSE OF GRAFT FAILURE Other (Record from list)

55 MONOCLONAL / POLYCLONAL THERAPY (Record from list)

COURSE	DATE	AGENT	OTHER	NUMBER OF DOSES GIVEN	REASON	OTHER
1st						
2nd						
3rd						

56 TOTAL DAILY DRUG DOSE (mg)

	TOTAL INITIAL ORAL DOSE	1 MTH	2 MTH	3 MTH	6 MTH	1 YR	2 YR	3 YR	5 YR	7 YR	10 YR	15 YR	20 YR	25 YR	30 YR	35 YR
CYA																
AZA																
PRED																
TACROL																
MMF																
SIROL																
OTHER																

57 CYA SPARING DRUG 0=NOT GIVEN 1=GIVEN (eg DILTIAZEM - KETOCONAZOLE - VERAPAMIL)

58 BODY WEIGHT (kg)

59 SERUM CREATININE µmol/L

FOR OFFICE USE ONLY

60 HLA TYPING

	BLOOD GROUP	A		B		DR		DQ	
RECIPIENT									
DONOR									

61 PRA AND CROSSMATCH

MAXIMUM	CURRENT

INSTRUCTIONS FOR DIALYSIS AND TRANSPLANTATION SURVEY COMPILATION
PLEASE READ THE EXPLANATORY NOTES BEFORE COMMENCING TO FILL IN THE FORMS
Please complete the form using neat capitals

5 – RACIAL ORIGIN
1 Caucasoid
2 Australian Aborigine
3 Chinese
4 Maori
5 Arab
61 Cook Islander
63 Samoan
64 Tongan
65 Torres Strait Islander
69 Pacific People — other (specify)
7 Indian
8 Indonesian
9 Malay
10 Filipino
11 Vietnamese
20 Other (specify)
00 Patient objects to answering question

Mixed race coded by patient/s assessment

6 - PRIMARY RENAL DISEASE
Results of ANCA (Anti Neutrophil Cytoplasmic Antibody) test in association with glomerulonephritis should be entered in box marked OTHER

100 Presumed GN, type undefined histologically (no biopsy)
110 Focal sclerosing GN (including hyalinosis)
111 Primary focal sclerosing GN or focal glomerular sclerosis
112 Secondary focal sclerosing GN
121 Mesangiocapillary GN with subendothelial deposits (double contour)
122 Mesangiocapillary GN with intramembranous deposits (dense deposit disease)
130 Membranous GN
140 Extra and intra capillary GN (extensive crescents - clinically rapidly progressive)
151 Mesangial proliferative (IgA+ positive)
152 Mesangial proliferative (IgA- negative)
153 Mesangial proliferative (no I.F. studies)
160 Focal and segmental proliferative GN (including focal necrotising)
170 Advanced GN (unclassified = end stage)
180 GN with systemic disease (specify)
181 Goodpasture/s syndrome with linear IgG and lung haemorrhage
182 Proliferative GN with linear IgG -no lung haemorrhage
183 SLE
184 Henoch-Schonlein purpura
185 Wegener/s Granulomatosis
186 Microscopic Polyarteritis
187 Scleroderma
190 GN other (specify)
191 Familial GN (specify Alport/s - yes or no)
200 Analgesic nephropathy
300 Renal vascular disease due to malignant hypertension (NO primary renal disease)
301 Renal vascular disease — type unspecified
302 Renal vascular disease — due to hypertension (nephrosclerosis) (NO primary renal disease)
303 Atheroembolic disease (cholesterol emboli)
304 Bilateral renal artery stenosis
400 Polycystic kidney disease
401 Medullary cystic disease
402 Infantile/juvenile polycystic kidney disease
500 Reflux nephropathy
600 Pyelonephritis
700 Calculi
701 Gout
801 Diabetes — Type 1 (insulin dependent) **[Juvenile onset]**
802 Diabetes — Type 2 (non-insulin requiring)
803 Diabetes — Type 2 (insulin requiring) **[Mature onset]**
900 Other (specify)
001 Uncertain diagnosis
002 Lead nephropathy
003 Cadmium toxicity
004 Renal tuberculosis
005 Amyloid disease
006 Haemolytic uraemic syndrome
007 Cortical necrosis
008 Interstitial nephritis
009 Congenital renal hypoplasia and dysplasia
010 Loss of single kidney (specify - e.g. trauma, surgery)
011 Megaureter
012 Oxalosis
013 Cystinosis
014 Balkan nephropathy
015 Renal cell carcinoma (GRAWITZ)
016 Transitional cell carcinoma of urinary tract
017 Paraproteinaemia (including multiple myeloma)

PRIMARY RENAL DISEASE cont/d
018 Light chain nephropathy (benign)
019 Lithium toxicity
020 Post partum nephropathy
021 Sarcoidosis
031 Posterior urethral valves
032 Pelvi-ureteric junction obstruction
033 Obstructed megaureter
034 Neuropathic bladder
035 Non-obstructed dilated bladder and ureters (megacystitis — megaureter)
036 Spina bifida or myelomeningocoele
037 Bladder neck obstruction (incl. prostatomegaly)
039 Other lower urinary tract abnormalities (with secondary reflux) (specify)
040 Ureteric obstructive nephropathy
041 Obstructive nephropathy

16 - CAUSE OF DEATH
CARDIAC
10 Myocardial ischaemia (presumed)
11 Myocardial ischaemia and infarction
12 Pulmonary oedema
13 Hyperkalaemia
14 Haemorrhagic pericarditis
15 Hypertensive cardiac failure
16 Cardiac arrest — cause uncertain
17 Other causes of cardiac failure (specify)

VASCULAR
21 Pulmonary embolus
22 Cerebrovascular accident
23 Gastrointestinal haemorrhage
24 Haemorrhage from dialysis access site
25 Haemorrhage from transplant artery
26 Aortic aneurysm — rupture
27 Haemorrhage from elsewhere (specify)
28 Bowel infarction

INFECTION
Please enter code for nature of infective organism, after the code for site of infection Please **specify type of organism**
eg Staph, CMV, Candida, etc

eg 321 Lung infection — bacterial (staph)
322 Lung infection — viral (CMV)

31 CNS	1 Bacterial
32 Lung	2 Viral
33 Urinary tract	3 Fungal
34 Wound	4 Protozoa
35 Shunt	5 Other
36 Peritoneum	
37 Septicaemia — site unknown (specify organism)	
38 Liver (incl. viral hepatitis) (specify A, B, CMV, herpes, etc)	
39 Other site (specify)	

SOCIAL
40 Withdrawal for psycho-social reasons
41 Patient refused further treatment (specify reason)
42 Suicide
43 Therapy ceased for any other reason (specify reason)
44 Accidental death (specify)
45 Withdrawal for cardiovascular comorbid conditions
46 Withdrawal for cerebrovascular comorbid conditions
47 Withdrawal for peripheral vascular comorbid conditions
48 Withdrawal related to malignancy
49 Withdrawal related to dialysis access difficulties (AVF, Tenckhoff, etc)

MISCELLANEOUS
50 Hepatic failure (specify)
51 Uraemia caused by graft failure
52 Pancreatitis
53 Bone marrow depression
54 Cachexia
55 Unknown
56 Malignant disease
57 Perforation of abdominal viscus — peptic ulcer, diverticulum, appendix
58 Dialysis dementia (aluminium)
59 Other (specify)
60 Immunodeficiency due to viral infection (specify organisms involved)
61 Chronic respiratory failure
62 Sclerosing peritonitis

19 – TYPE OF DIALYSIS
11 Haemodialysis — plate dialysers
12 Haemodialysis — hollow fibre dialysers
15 Haemofiltration
16 Haemodiafiltration
19 C.V.V.HD (Intensive Care Unit)
20 Peritoneal — bags no cycler
21 Peritoneal — continuous ambulatory (CAPD)
22 Peritoneal — automated (APD)
23 Peritoneal — intermittent cycler (IPD)
25 Peritoneal — other (specify)

20 – DRY WEIGHT
At end of survey, transplantation or death.

21 – UNCORRECTED CALCIUM
Not corrected for albumin
Midweek, predialysis and closest to end of survey, transplantation or death.

22 – PHOSPHATE
Midweek, predialysis and closest to end of survey, transplantation or death.

23 – HAEMOGLOBIN
Midweek, predialysis and closest to end of survey, transplantation or death.

31 – URR or Kt/V Please enter method used
A Urea Reduction Ratio % (URR%)
B Kt/V (by BIOSTAT)
C Kt/V (by UKM)
D Kt/V (by DAUGIRDAS — single pool)
E Kt/V (other method — specify)

Kt/V (for HD patients) Range 0.5 — 2.2

UREA REDUCTION RATIO %

(Pre dialysis urea — post dialysis urea) x 100 = **URR%**
Pre dialysis urea

Pre dialysis urea:
Blood should be drawn from the arterial/ needle immediately prior to dialysis, at a mid-week dialysis session

Post dialysis urea:
Blood is again drawn from the arterial/ needle and this should occur **within 20 seconds** after cessation of the blood pump (alternatively the pump can be turned down to 50 ml/min) — this is to avoid problems with recirculation

32 – ACCESS IN USE
Type at First HD - leave blank if initial renal replacement treatment was not haemodialysis.

Type at Last HD - enter for all patients on haemodialysis at any time during the survey. Enter the procedure closest to the end of survey, change to PD, transplantation, or death.

33 – PET TEST (Required **Once Only** per patient)
Standard Peritoneal Dialysis Equilibration Test
performed 1-6 months after initiation of PD
(2.5% 2 litre exchanges)

Provide dialysis/plasma creatinine at 4 hours
Range 0.1 — 1.2

38 to 40 – PD CLEARANCE STUDIES
Generated from a 24 hour collection of PD effluent and urine

NOTE: Dialysate Creatinine Clearance and Kt/V both refer to dialysis clearances ONLY (NOT the total of dialysis and renal clearances).

38 DIALYSATE ONLY (Creatinine Clearance)
Range 10 - 200 litres/week
Litres /week /1.73m² Body Surface Area

39 DIALYSATE ONLY WEEKLY Kt/V - **Range** 0.1 — 5.0

40 RESIDUAL RENAL FUNCTION
(Creatinine Clearance)
Litres /week /1.73m² Body Surface Area

41 – REASON FOR TRANSFER
*** From CAPD to APD**
*** From APD to CAPD**
*** From any form of PD to HD**

10 Recurrent / persistent peritonitis
11 Acute peritonitis
15 Tunnel / exit site infection
16 Diverticulitis
20 Inadequate solute clearance
21 Inadequate fluid ultrafiltration
27 Abdominal abscess
30 Dialysate leak
31 Catheter block
32 Haemoperitoneum
35 Hernia
36 Abdominal pain
40 Abdominal surgery
41 Sclerosing peritonitis
45 Haematuria
46 Pleural effusion
50 Patient preference
51 Unable to manage self-care
60 Recovery of renal function
70 Transplantation
80 Death
81 Transfer outside Australia
82 Other surgery
83 Hydrothorax
99 Other (specify)

49 – SOURCE OF DONOR KIDNEY
1 Deceased Donor
2 Sister (if twin, record 6 or 7)
3 Brother (if twin, record 6 or 7)
4 Mother
5 Father
6 Monozygotic (identical) twin
7 Dizygotic (non-identical) twin
8 Other related living donor (specify)
9 Son
10 Daughter
11 Husband
12 Wife
13 Cousin
14 Unrelated living donor (specify)

50 – TOTAL ISCHAEMIA (HOURS)
From time of donor renal artery interruption or aortic clamp, until time of release of renal artery in the recipient (clamp off)

51 – IMMEDIATE FUNCTION
1 Spontaneous fall in se.creatinine by 10% within 24 hours

2 Spontaneous fall in se.creatinine by 10%, first recorded between 25-72 hours

3 Poor immediate function. No spontaneous fall in se.creatinine within 72 hours; but no dialysis needed

4 No immediate function. No spontaneous fall (> 10%) in se.creatinine; dialysis required within 72 hours

52 – DISEASE IN GRAFT **Histologically proven**
Complete this section for **FUNCTIONING or FAILED GRAFTS**

Please enter **Date first proven (e.g. Graft Biopsy)**

B = BK virus nephropathy in graft

Y = Disease recurrence
— primary renal disease and disease in graft the same

D = De novo glomerulonephritis
— primary renal disease known and not the same

G = Glomerulonephritis in graft
— primary renal disease unknown or not biopsied

In cases of glomerulonephritis, where histological confirmation of recurrence may be uncertain, enter as G

54 – CAUSE OF GRAFT FAILURE
REJECTION
10 Hyperacute rejection (within 48 hours of transplantation)
20 Acute rejection at anytime, causing graft failure
40 Chronic allograft nephropathy (slow progressive loss of renal function, not due to recurrent original disease or acute rejection)

VASCULAR
50 Renal artery stenosis
51 Renal artery thrombosis
52 Renal vein thrombosis
53 Renal vessel haemorrhage (primary)
54 Renal vessel haemorrhage (secondary)
55 Embolus — thrombo
56 Embolus — cholesterol
57 Haemolytic uraemic syndrome

TECHNICAL
60 Non-viable kidney (due to pre-transplant cortical necrosis)
61 Cortical necrosis post transplant (not due to rejection)
70 Ureteric and bladder problems

GLOMERULONEPHRITIS
82 Mesangiocapillary GN with subendothelial deposits
83 Mesangiocapillary GN with intramembranous deposits (dense deposit disease)
84 Focal sclerosing GN (including hyalinosis)
85 Membranous GN
86 Mesangial proliferative GN (IgA positive)
87 Goodpasture/s syndrome
88 Intra and extra capillary GN with extensive crescents (clinically rapidly progressive)
89 Other (specify)

DRUG THERAPY
90 Complications of drug therapy requiring reduction or withdrawal of steroid and/or immunosuppressants
91 Non-compliance with therapy — causing graft failure
92 Rejection following I/S reduction due to malignancy
93 Rejection following I/S reduction due to infection

MISCELLANEOUS
00 Other (specify)
01 Donor malignancy
02 Malignancy invading graft
05 BK virus nephropathy

55 – MONOCLONAL / POLYCLONAL THERAPY
Record in order of administration, each separate course of such drugs; a second course of the same drug should be separately recorded
Complete the requested details regarding, date, identity of drug, number of doses given, and reason for administration, according to the following codes

TYPE OF AGENT	NUMBER OF DOSES
2 Daclizumab (Zenepax)	Record actual number of doses given
4 OKT3	
5 Intravenous Immunoglobulin	
6 Basiliximab (Simulect)	
7 Rituximab	
8 Polyclonal anti T cell	
9 Other monoclonal (specify)	

REASON FOR USE
1 Prophylaxis
7 Treatment for acute rejection
8 Other (specify)

56 – TOTAL DAILY DRUG DOSE
Enter the total daily dose for each drug where applicable; if an unlisted drug is used, enter the name in the space provided marked **OTHER**

Only those drugs taken at the listed intervals should be entered; where necessary provide the dose recorded on the closest day preceding the requested time interval

The initial drug dose (at zero months) is **the first oral maintenance dose**; do **NOT** enter the intravenous loading doses administered at or shortly after transplantation

(2005)

SUMMARY

KEY SUMMARY POINTS

AUSTRALIA

- There were 14,221 patients (707 per million) receiving renal replacement therapy (RRT) at 31st December 2004. Of these, 6,269 (312 per million) had a functioning kidney transplant and 7,952 (395 per million) received dialysis treatment.
- 1,912 patients commenced RRT in Australia in 2004 (95 per million). The intake varied from 395 per million population in the Northern Territory to 64 per million in Tasmania.
- The mean age at commencement was 59.5 years.
- 25% of new patients had glomerulonephritis attributed as their cause of end stage renal failure, 30% diabetic nephropathy, and 13% hypertension.
- Of patients <65 years of age and receiving dialysis treatment, 33% were on the active kidney transplantation waiting list. This proportion varied between 7% in the Northern Territory and 48% in the Australian Capital Territory. Only 6% of Aboriginal/Torres Strait Islander patients <65 years were on the transplant waiting list.
- The death rate per 100 patient years was 15.4 for dialysis dependent patients (haemodialysis 15.2, peritoneal dialysis 16.0) and 2.0 for those with a functioning kidney transplant (cadaver donor 2.4, live donor 1.1).
- Of the 1,205 deaths among dialysis dependent patients in 2004, 40% were due to cardiovascular causes, 14% to infection, 27% to withdrawal from treatment and 5% from malignancy.
- Of the 125 deaths among patients with kidney transplants, 22% were due to cardiovascular causes, 39% due to malignancy and 21% to infection.
- There has been a 3% increase in the total number of prevalent dialysis patients.
- The numbers of peritoneal dialysis dependent patients decreased by 9% from 1,840 to 1,778 in 2004.
- There were 649 kidney transplant operations performed in 2004, a transplant rate of 32 per million population.
- Of these, 37% (243 grafts) were from live donors, compared to 40% (243 grafts) in 2003. 22% of live donor operations were performed without the recipient receiving prior dialysis therapy.
- For primary deceased donor grafts performed in 2003-04, the 12 month patient and graft survival rates were 96% and 90% respectively.
- The five year primary deceased donor recipient and graft survival for operations performed in 1997-98 were 86% and 77% respectively.
- There were 6,269 functioning kidney transplants in Australia at 31st December 2004, a prevalence of 312 patients per million (a 5% increase over 2003).

KEY SUMMARY POINTS

NEW ZEALAND

- There were 2,994 patients (737 per million) receiving renal replacement therapy (RRT) at 31st December 2004. Of these, 1,224 (301 per million) had a functioning kidney transplant, and 1,770 (436 per million) received dialysis treatment.
- 447 patients (110 per million) commenced RRT in 2004.
- The mean age at commencement was 57.5 years.
- Diabetic nephropathy accounted for 40% of new patients and glomerulonephritis 24%.
- Of patients <65 years of age, 24% were on the active kidney transplantation waiting list. 22% of Maoris and 16% of Pacific People <65 years of age were on the transplant waiting list.
- The death rate per 100 patient years was 17.3 for dialysis dependent patients (haemodialysis 15.2, peritoneal dialysis 20.0) and 2.1 for those with a functioning kidney transplant (cadaver donor 2.3, live donor 1.6).
- Of the 301 deaths among dialysis dependent patients in 2004, 51% were due to cardiovascular causes, 12% to infection, 22% to withdrawal from treatment and 5% from malignancy.
- Of the 25 deaths among patients with a kidney transplant, 12% were due to cardiovascular causes, 32% due to malignancy and 24% due to infection.
- The number of patients who were dialysis dependent at 31st December 2004 (1,770) was an increase of 3% over the previous year. 56% of all dialysis dependent patients were receiving home dialysis. 75% of these were on peritoneal dialysis.
- The reported haemoglobin and use of erythropoietic agents have continued to increase over recent surveys.
- There were 105 kidney transplant operations performed in 2004, a rate of 26 per million population.
- The percentage of live donors in 2004 was 46%.
- For primary deceased donor grafts performed in 2003-04, the 12 month patient and graft survival rates were 95% and 89% respectively.
- The five year primary deceased donor recipient and graft survival for operations performed in 1997-98 were 84% and 73% respectively.
- The 1,224 functioning kidney transplants at 31st December 2004, a prevalence of 301 per million represents a 5% increase from 2003.